

LUPUS LINE

Lupus Foundation of America, Philadelphia Tri-State Chapter, Inc.



From the Chair...

Ten years ago I lost my aunt to lupus. At the time, it left a hole in my heart. I found solace in the words of Helen Keller: "What we have once enjoyed we can never lose. All that we love deeply becomes a part of us." Over time I filled that hole in my heart with memories of Cindy, and with the resolve to fight against lupus in her honor. Cindy and lupus will always be a part of me.

Therefore, although my term as Chair of the Board of Directors ends this month, there's no point in saying goodbye. First, the Arnold family will continue its strong support of the Philadelphia Tri-State Chapter and Team Haas will always be a presence at the Lupus Loop. Second, the Chapter's work is hardly finished, so it seems silly to pat ourselves on the back when we have so much more to accomplish. This will not be a lengthy, emotional, "goodbye column."

Instead, I would like to take this opportunity to recognize and thank a lot of very deserving people. First and foremost, many thanks to you, our readers, donors and volunteers, who continue to support us during an extended economic downturn that has forced many non-profits to close their doors. We cease to exist without the financial support we get from unrestricted donations, membership fees, and special events.

Next, thank you so very much to our dedicated Board Members, past, present and future. Our Board Members carve out time away from family and work to map the future of the Philadelphia Tri-State Chapter and ensure that we advance our mission. My predecessors, Hope White and Eileen Harmon Council, laid a foundation for leadership that will be carried forward by our incoming Board Chair, Debra Riegel Jepson. Deb, who battles lupus with dogged determination and bravery, is an inspired choice to lead the Chapter. My deepest thanks to Dr. Laura McCloskey and Cheri Perron, who rotate off the Board after six years of service marked by many years on the Executive Committee and by immeasurable contributions to the Chapter.

Thank you to our Chapter Staff, who breathe life into our mission every day, who wear the lupus cause on their sleeves, and who have just the right words for everyone, be it a scared lupus patient, a Congresswoman, a rheumatologist, or potential donor.

Finally, please indulge me in a brief moment of selfishness while I thank my family for supporting the Foundation for well over twenty years. My parents, sister, aunts, uncles and cousins are all dedicated volunteers and donors. My grandmother, Bev Haas, my personal hero, has fought tooth and nail against lupus since Cindy's diagnosis in 1991. And to my wife, Danielle, my son Caden and his soon-to-be little sister, thank you for supporting my pursuit of this worthy cause and listening to me complain about the difficulties of conducting Board business via conference calls.

At this point, I'm sure the Chapter Staff would like me to get on to Chapter business. Past newsletters have addressed our territorial expansion to Southern New Jersey and Delaware, the FDA's historic approval of Benlysta, the importance of sharing your lupus story during Lupus Awareness Month, and so on. This one is all about the Lupus Loop.

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(From the Chair continued...)

Believe it or not, we were doing the Lupus Loop 20 years ago. We would like to commemorate this, our 20th anniversary, with our most successful and most inspirational Lupus Loop yet. Thanks to the overwhelming success of the Washington D.C. (\$300k+) and Atlanta (\$400k+) Walk For Lupus Now events this past spring, we set a very aggressive but attainable goal of \$295,000. To accomplish this, we ask that you take ownership of the Loop. By way of example, consider hosting a pre-Loop fundraiser, think about potential corporate sponsorship opportunities for your team, or call the office to discuss volunteer opportunities for student groups.

I leave you with a final thought. The early Lupus Loop events in the mid 1990's bring back memories of extremely cold, dark mornings at Memorial Hall with a couple hundred people huddled under blankets. This stands in stark contrast to the magical Lupus Loops of recent years. Upon reflection, the weather has always been about the same, it's my perception that has changed. Walking amongst thousands of people with a common goal to cure lupus fills that hole in my heart and provides all the sunshine we need.

Joseph Arnold
Chair



This Fall...*Please Remember Us* During Your Annual Workplace Giving Campaign!

Please remember us during your Annual Workplace Giving Campaign! You may use the following Donor Option Numbers to designate the Lupus Foundation of America, Philadelphia Tri-State Chapter as a beneficiary:

United Way of Southeastern PA: 1071

United Way of Delaware: 1179

**PA State Employee Combined Appeal (SECA)
giving through CHC: 2000-0013**

**Philadelphia School District Employees
giving through United Way: 1101071**

**City of Philadelphia Employees' Campaign:
14-0018**

**Delaware State Employees' Charitable
Campaign (SECC): 50144**

**Combined Federal Campaign in greater
Philadelphia: 21928**

Combined Federal Campaign in DE: 32083

**Combined Federal Campaign in Southern NJ:
21928**

Don't forget...many employers match contributions made by their employees to qualifying charitable organizations. Contact your personnel or community relations department for a copy of the matching gift forms. Complete this form and include it with your gift. The LFA Philadelphia Tri-State Chapter will fill in the required verification information and mail the form to the appropriate company contact.

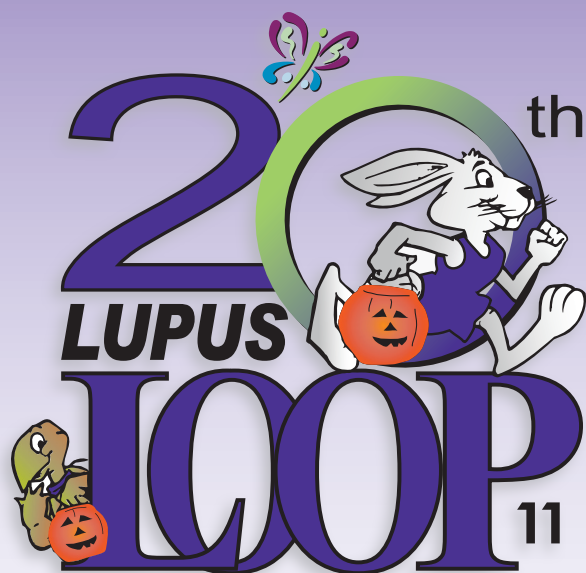
Hortense Guggenheim Grant-in-Aid

Established by the late Hortense F. Guggenheim, this fund provides financial help for people with lupus who are unable to pay for essential medications and other lupus-related expenses. We are deeply indebted to the members of the Guggenheim Family and their friends who have sustained this philanthropic program. If you, or someone you know are in need of assistance, we may

be able to help. Please call 215-517-5070 to request a grant application.

Please consider giving an additional gift to the Hortense Guggenheim Grant-in-Aid Fund this year so we may continue to offer assistance to those in need. You may use the enclosed membership application/contribution envelope to send a donation.

www.lupustristate.org



Sunday, October 30, 2011

7:30 am Registration

9:00 am Starting Time

Memorial Hall Loop

Across from the Please Touch Museum

Avenue of the Republic & West Memorial Hall Drive
Philadelphia, PA

Benefiting the Lupus Foundation of America Philadelphia Tri-State Chapter

215.517.5070

Toll-Free (PA, NJ & DE) 866.517.5070

www.lupusloop.org



The campaign for the 20th Annual Lupus Loop 5K Run and 2.5 Mile Walk for Lupus Now is well underway! With your support, we hope to draw more than 4,000 walkers, runners, volunteers and supporters to participate in the event which takes place on Sunday, October 30, 2011 in Fairmount Park, Philadelphia.

"On our anniversary walk, we are thrilled to celebrate another milestone," said Annette Myarick, CEO for the Lupus Foundation of America (LFA), Philadelphia Tri-State Chapter. "Earlier this year the U.S. Food and Drug Administration (FDA) approved the first new treatment for lupus in more than 52 years! It signals

a new era of improved treatment for the disease, and offers hope for a better quality of life for the over 40,000 people in the Philadelphia Tri-State Region living with lupus."

Proceeds from the Lupus Loop 5K Run and 2.5 Mile Walk for Lupus Now support the programs and services of the Philadelphia Tri-State Chapter, including research. This year's event marks the 20th annual event, the LFA's oldest walk in the country. For more information or to register visit www.lupusloop.org or call 215-517-5070 (PA/NJ/DE 866-517-5070).

A Story of Hope

My name is Caitlin Keane, and I am the team captain of Caitlin's Team. I walk in the Lupus Loop because I was diagnosed with lupus when I was sixteen years old. Funding for research comes through awareness; therefore I try to make lupus awareness a part of my life every day. Most people I meet do not know what lupus is, yet it is a very common disease. I created a team in the Lupus Loop to spread the word about lupus and let everyone around me know what they can do to help find better treatments, and hopefully someday soon, the cure!

My advice for other Loop participants is to never be afraid to ask for contributions! People are willing to help this important cause, but unless you explain to them how they can help, they won't know.

The Lupus Loop has helped me to deal with daily life with lupus because I am not just letting the disease control me; I am fighting back. Living with lupus is very difficult, but knowing that thousands of people come together each year to support people with lupus just like me and our families helps me to stay positive.



Caitlin at the
2008 Lupus Loop

Our thanks are extended to:

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Put Our 50 Years of Experience to Work For You

Bronze Sponsor:



Pennsylvania's Children's
Health Insurance Program
We Cover All Kids.

www.chipcoverspakids.com



www.kidzpartners.com

The U.S. Department of Defense Awards \$2.3 Million in Funding for Lupus Research

The Lupus Foundation of America (LFA) and its network of Chapters congratulate Trine Jorgensen, Ph.D., Assistant Staff, Department of Immunology, Cleveland Clinic Foundation and I-Cheng Ho, M.D., Ph.D., Associate Physician, Brigham and Women's Hospital, for being selected to receive research grants totaling \$2.3 million from the U.S. Department of Defense's (DoD) Congressionally Directed Peer Reviewed Medical Research Program (PRMRP).

The DoD awarded Dr. I-Cheng Ho \$1.2 million to fund a study that will examine a protein called Ets1 to determine if it can counteract the disease process of lupus. It is believed that the function of Ets1 may be impaired in people with lupus, and this research may help to better understand the cause of lupus.

Dr. Trine Jorgensen was awarded \$1.1 million to further study why females are disproportionately affected by lupus. Nine out of ten people with lupus are female—a disparity that remains unexplained. Dr. Jorgensen's studies will explore the role of a population of immunosuppressive cells in the development of lupus, and analyze related mechanisms of disease suppression as it may occur in males.

Through its advocacy initiatives that began in 2003, the Lupus Foundation of America (LFA) pioneered efforts to have lupus included as a disease area eligible for research funding through the PRMRP. The LFA has continued to demonstrate to Congress the relevance of lupus research to military personnel and their dependents. These efforts have opened an additional source of much-needed funds to support research on lupus. To date, \$11.8 million has been awarded to lupus researchers through the PRMRP.

Funding for lupus research through the DoD and other relevant federal agencies has been a long-recognized priority for LFA advocacy efforts. Due to the changing demographics of the military population, there is an ever-increasing prevalence of lupus in military. The LFA recognized this emerging health issue and worked to have lupus included in the PRMRP to advance research on lupus, which ultimately will help military personnel and their families affected by lupus.

To learn more, visit the DoD's Congressionally Directed Peer Reviewed Medical Research Program's Web site at <http://cdmrp.army.mil/prmrp/>.

Great Gift Ideas

*for Holidays, Birthdays or
any Special Occasions...*

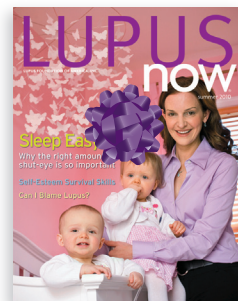


Tributes

This year, consider making a donation in honor/memory of a loved one in lieu of a present, and we will send a beautiful acknowledgement card to the recipient(s). Your gift will be fully tax-deductible and will go towards the Lupus Foundation of America, Philadelphia Tri-State Chapter's vital mission of finding the causes of and cure for lupus, and providing support, services and hope to all people affected by lupus. We've made donating convenient by offering many choices: you may give online at www.lupustristate.org, by sending a check into our office at 500 Old York Road, Suite 110, Jenkintown PA 19046 or by calling us at 215-517-5070.

Membership

Become a member today, or give a gift membership to that someone you know with lupus and show your support of the Philadelphia Tri-State Chapter! Among the many perks of membership is a subscription to *Lupus Now*, the nationally-ranked magazine published by the National Lupus Foundation of America. It comes packed with useful information on resources, living with lupus, medication and much more.



LFA Research Initiative: Center for Clinical Trials Education

The Lupus Foundation of America is dedicated to **Bringing Down the Barriers** that for decades have obstructed basic biomedical, clinical, epidemiological, behavioral, and translational research on lupus. We are committed to accelerating the pace of medical discovery in lupus with the clear goal of making clinical research more feasible. LFA is working through its **Center for Clinical Trials Education (CCTE)** and **Lupus Research Registry** to distribute information about clinical research studies currently seeking volunteers. As part of the LFA, Philadelphia Tri-State Chapter mission, we want to inform you of opportunities to learn more about clinical research participation and specific studies seeking participants in our community.

Clinical research studies are conducted to learn more about drugs that are in development (investigational drugs). All drugs must go through several phases of clinical research to evaluate their safety and effectiveness before they can be made available for use by the general population.



The EMBODY program is a global clinical research program testing the safety and effectiveness of an investigational study drug called epratuzumab in people with moderate to severe lupus. As part of the EMBODY program, two clinical research studies are being conducted at over 300 participating study sites in approximately 30 countries worldwide. Approximately 780 people are expected to participate in each study. To find out more information, including participants eligibility requirements, go to www.EMBODYprogram.com and the LFA CCTE Study Spotlight at www.lupus.org/clinicaltrials/study-spotlight.html.

MEMORIALS AND TRIBUTES

Our Officers and Board Members extend heartfelt sympathy to the loved ones of those whose names follow, and in whose memory we received thoughtful gifts. We also thank those making donations in honor of friends and loved ones. These Memorials and Tributes were received during the months of April 2011 to August 2011.

IN MEMORY OF

PATRICIA HENNESSY AMBROSIOUS

Patricia R. Ambrosius

JIM BARBATO

Mike & Renee Samson

EMILY BEEKLEY

Barbara Stickley

BROTHER OF DR. & MRS. MURRAY LEVYN

Ruth & Fred Milstein

GERALD CABIN

Mike & Renee Samson

BETTY ANN COHEN

Margery Bernheim

MARVIN FARBSTAIN

Alisha Katz
Mike & Renee Samson

RENEE FERACO

Karl & Mary Knapp
Vardaro Family

STAN FRIEDMAN

Beverly Haas

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Human Resources at
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www.lupustristate.org

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IN HONOR OF

SUSAN ALEXANDER & STANLEY WISE

*Congratulations on your
Wedding*
Dorothy Sacks
Ruth Singer

ELLEN H. ALLEN

Happy Mother's Day Grandmom
Anica & Danielle

DEBBIE APALUCCI

Happy Mother's Day
Sally Apalucci

JENN ARSENAULT

Happy Mother's Day
Sally Apalucci

DIANE CROCE

Happy Mother's Day
Sally Apalucci

MARILYN DEUTSCH

Mazel Tov!
Phyllis & Billy Schwartz

PATTY ELLER

Happy Mother's Day
Sally Apalucci

ROBIN GLEASON

Happy Mother's Day
Sally Apalucci

IRENE GREENSTEIN

Special Birthday
Nettie Kutikoff

JENNIE HENEKS

Happy Mother's Day
Sally Apalucci

SALLY HENNESSEY

Happy Mother's Day
Sally Apalucci

MELISSA KERNS

Happy Mother's Day
Sally Apalucci

TARA LIBERATORE

Happy Mother's Day
Sally Apalucci

MEMORIALS AND TRIBUTES | MEMBERSHIP 2011

Our Officers and Board Members extend heartfelt sympathy to the loved ones of those whose names follow, and in whose memory we received thoughtful gifts. We also thank those making donations in honor of friends and loved ones. These Memorials and Tributes were received during the months of April 2011 to August 2011.

CATHY OLSEN

Berger & Sylvia Hausvik

KAIJA POWERS

Happy Mother's Day

Sally Apalucci

MICHELE ROOSEVELT

Happy Mothers Day

Sally Apalucci

ANDREW SACKS

In Your Honor

Sarah G. Mintz

ERIN SALZANO

Happy Mother's Day

Sally Apalucci

WOOEY SCHMUCKER

Happy Mother's Day

Sally Apalucci

BETH SCHWARTZ

Happy Mother's Day

Sally Apalucci

DR. ARLYNE SHOCKMAN

Good Luck with the Tournament

Lea Bramnick

JANET SIMMERMAN

Steven Simmerman

GOLDIE SIMON

A Speedy Recovery

Norma, Ken, Laura & Tim

SUSAN SMITH

Happy Mother's Day

Sally Apalucci

CATHY SMYTH

Happy Mother's Day

Sally Apalucci

KELLY SORG

Happy Mother's Day

Sally Apalucci

JAN TERRILL

Happy Mother's Day

Sally Apalucci

STACEY VARALLO

Happy Mother's Day

Sally Apalucci

DIANE VENUTO

Happy Mother's Day

Sally Apalucci

GRAM VENUTO

Happy Mother's Day

Sally Apalucci

CINDY VENUTO-PHILLIPS

Happy Mother's Day

Sally Apalucci

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Happy Mother's Day

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Michelle Stuhl
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Michele Taylor
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Rose Boyer-Wilcox
Vickie Williams
Charles Wilson
Myra Wolf
Junnell Woods

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Angel Barrett
Sade Benton
Vanessa Berry
Linda Brecher
Shirley Breslin
Dionne Bright
Athleen Brown
Susan Cornwell
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Sandra Dolan
Arletha Fluellen
Catherine Foley
Maureen Ginnane
Michelle Carter-Goldsmith
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Catherine Lange
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SAVE THE DATE

for Upcoming Fall and Winter Events

Advances in Lupus Research: Spotlight on Treatment

Live Webinar with Leading Lupus Experts

5:30 – 6:30 pm

Wednesday, October 26, 2011

Parents Caring for Children with Lupus Teleconference

Saturday, November 19, 2011

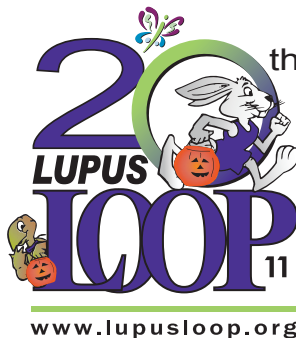
1:00-2:00pm

Presenter: Emily von Scheven, M.D.

20th Annual Lupus Loop

Sunday, October 30, 2011

Memorial Hall Loop in Fairmount Park, Philadelphia, PA



Use this code to get
started at lupusloop.org

Lupus Line is a publication of the Lupus Foundation of America (LFA), Philadelphia Tri-State Chapter, Inc.

If you have any questions or comments, please feel free to call the office at 215-517-5070.

Or you can write to us at: LFA, Philadelphia Tri-State Chapter, Rydal Square, 500 Old York Road, Suite 110, Jenkintown, PA 19046

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